CHAPTER 1

Vulnerable Older Adults: A Population Demanding Attention

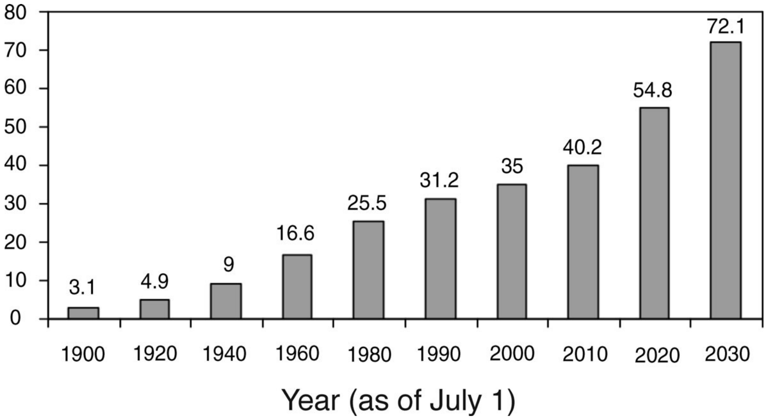
IMPACT OF DEMOGRAPHICS ON SOCIAL WORK PRACTICE

The population in the United States and most other countries in the world is aging dramatically. In 2007, individuals over age 65 composed 12.6 percent of the population in the United States. By the year 2030, projections indicate that 72.1 million Americans will be over age 65 (see Figure 1) and that older adults then will make up nearly 20 percent of the U.S. population (U.S. Department of Health and Human Services [DHHS], Administration on Aging, 2008). Especially significant is the fact that projections show that the greatest increase will be among the oldest and most vulnerable subgroup of seniors, those over 85 years of age (DHHS, Administration on Aging, 2008; Hooyman & Kiyak, 2005). In 2000, adults over 85 years of age accounted for approximately 12 percent of the total senior population (Americans over age 65); by 2050, projections indicate that adults over age 85 will account for approximately 21 percent of Americans over age 65 (DHHS, Administration on Aging, 2008).

These demographic trends are increasing the demand for highly skilled geriatric social work practitioners to work with older adults living in communities across the country. The Institute for Geriatric Social Work (IGSW) estimated that 28 percent of social workers work primarily with older adults (IGSW, 2005). In the NASW survey *Assuring the Sufficiency of a Frontline Workforce*, 75 percent of the social workers who responded reported having older adults in their caseloads (Whitaker, Weismiller, & Clark, 2006). The number of social workers working with seniors will only increase as the percentage of seniors in this country booms.

Although the demand for social workers trained in geriatrics is growing, the number of social workers attending graduate MSW programs that offer an aging concentration or expanded courses on geriatrics is minimal. In its 2004 report

Figure 1: Numbers of People in the United States Age 65 and Older, 1900–2030



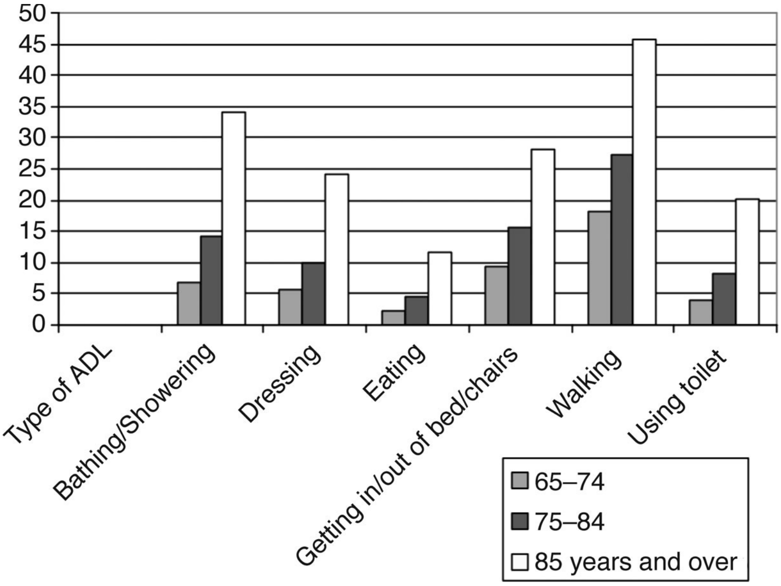
Notes: Adapted from Figure 1 (p. 3) in U.S. Department of Health and Human Services, Administration on Aging (2008). The *y*-axis represents numbers in millions.

An Aging Infusion: Gerontology Finds its Place in the Social Work Curriculum, the John A. Hartford Foundation reported that less than 3 percent of master's degree students were enrolled in gerontology programs in 2000; less than 10 percent of faculty members in 117 master's programs had formal training in aging; one-fourth of the 117 accredited master's programs lacked a single gerontology course; and two-thirds lacked even one field supervisor who was an expert in aging. As a result, social work graduates often lack the competencies they need to understand the complex requirements of older adults. A gap exists between the demands on the social work profession to work with older adults and their families and the preparation of the social work workforce to do so (CSWE, n.d.).

A growing concern in the field of gerontology is the steep rise in prevalence rates of functional incapacity among older adults, particularly those over the age of 85 (Wiener, Hanley, Clark, & Van Nostrand, 1990). The physical health of older people typically declines with increasing age while the likelihood of having a dementia escalates with age. In 2001, 24 million people worldwide had Alzheimer's disease and the expectation is that this number will rise to 43 million by 2025, and to 81 million by 2050 (Ferri et al., 2005). Adults age 85 and older are more likely to have a cognitive impairment and other coexisting health issues impairing their function (Wan, Sengupta, Velkoff, & DeBarros, 2005). A recent study found that limitations on activities of daily living increase with age, with the highest rate of limitations on activities of daily living occurring among people 85 and older (see Figure 2).

The majority of seniors who need long-term care are taken care of at home, with informal unpaid family care accounting for about 80 percent of caregiving activity (Kelly, 2008). The parent support ratio (the ratio of the population age 85 or over to that of ages 50 to 64) indicates that the level of support that families may be able to provide to their oldest members is decreasing worldwide. By 2050, people who are themselves well past middle age will be three times more likely than they are today to be responsible for the care of older relatives (United Nations,

Figure 2: Percentages of People with Limitations in Activities of Daily Living (ADLs), by Age Group: 2006



Notes: Adapted from Figure 9 (p. 14) in U.S. Department of Health and Human Services, Administration on Aging (2008). The *y*-axis represents percentages.

2007). Put otherwise, adults 85 years of age and older have the highest rate of limitations in their activities of daily living and are the fastest growing portion of the population, yet the level of support families may be able to provide (the parent support ratio) is projected to decrease. Given these trends, we anticipate more and more social workers and other healthcare professionals in the United States and throughout the world will find themselves working with vulnerable older adults.

VULNERABLE OLDER ADULTS

Vulnerable older adults are defined as seniors with limited cognitive or physical ability who are at risk for harm or neglect and seniors with impaired cognitive or physical ability who lack adequate support from family or an informal support network (Rothman, 1994). Vulnerable older people may present with a variety of problems. Examples include older individuals who are self-neglecting, hoarding, or socially isolated; those who suffer from mental illness or multiple coexisting health impairments; and elderly individuals who are facing eviction, homelessness, or other crisis situations. At times, social workers face challenging situations when the vulnerable older adult they are prepared to assist does not want help and refuses offered intervention and services. This can leave a social worker feeling frustrated, professionally inadequate and with great concern for the well-being of the older adult. Social workers often experience internal and external pressure to “do something” from their own value system, the referral source, or others in the older adult’s network.

Feeling frustration that one will have to "wait for the next crisis" before intervening is common.

Most professional codes of ethics include language that requires respect for clients' rights to self-determination. The legal, psychiatric, and medical professions have grappled with the difficult task of defining the scope, circumstances, and situations in which this right can be overridden (Moye, Butz, Marson, Wood, & the ABA–APA Assessment of Older Adults Working Group, 2007; Zarit & Zarit, 2007). In contrast, adult protective service (APS) workers, geriatric social workers, geriatric care managers, home care professionals, public health nurses, and other clinicians have limited guidelines for addressing similar situations they encounter in community-based practice (Davis, 1992, McCue, 1997). These professionals attempt to rely on both the legal concept of competence and the medical doctrine of informed consent. Although relevant, these concepts do not fully address the unique issues that confront professionals who attempt to work with "at-risk" clients who do not agree to accept help and who are still in the community setting.

PERSPECTIVES ON EVALUATING CAPACITY: SUMMARY BY DISCIPLINE

Medical or Informed Consent

Within health care, the medical literature relies on the concept of "informed consent" to ensure that its practitioners respect patients' rights to choose or refuse medical care. The doctrine of informed consent requires that the patient is provided sufficient information to make an informed decision; the patient makes the decision voluntarily, free from undue influence or duress; and the patient has decision-making capacity (Altman, Parmelee, & Smyer, 1992). The Uniform Health-Care Decisions Act defines *decision-making capacity* to give medical consent (or "consent capacity") as "an individual's ability to understand significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision" (National Conference of Commissioners on Uniform State Laws, 1993). An evaluation of decisional capacity generally considers the patient's ability to communicate a choice, ability to understand the relevant information, ability to appreciate the medical consequences of the situation, and ability to reason about treatment choices (Appelbaum, 2007). A risk–benefit ratio developed for conceptualizing medical decisions suggests that the degree of competence or level of capacity needed to give informed consent for treatment varies on the basis of degree of risk and benefit of the treatment (Appelbaum, 2007; Appelbaum & Grisso, 1988).

During the past 30 years, a substantial body of case law has focused on the issue of informed consent and surrogate decision making associated with medical practice. This literature, however, is not always relevant to community-based practice with "at-risk" clients. Most often, medical decisions involve consent for clearly defined procedures and short-term treatment interventions. Furthermore, the fact that the client has the cognitive capacity to give informed consent (consent capacity) does not address the question of whether or not the client has the functional capacity to live independently. In community-based practice with "at-risk" older clients, the issues are often less well defined and recommended interventions tend to be long term.

Psychology and Neuropsychology

Cognitive impairments in older adults can be caused by distorted thought processes caused by psychiatric problems (such as psychosis or severe depression) or they can be caused by deficits to neuropsychological functions in attention, short- and long-term memory, judgment, problem solving abilities, insight, expression of information, orientation to person, place and time, and other areas of cognition relevant to decision making (Zarit & Zarit, 2007). Various mental status exams are often used to evaluate the older adult's cognition. Psychological and neuropsychological evaluations of an older adult's cognitive ability are often sought in capacity evaluations. Neuropsychological tests can help clarify the causes of the cognitive impairment and then evaluate if any of the causes can be treated to decrease the cognitive impairment (American Bar Association [ABA] & American Psychological Association [APA], 2005; Zarit & Zarit, 2007). Psychological and neuropsychological assessments can also help differentiate between dementia and depression, identify if the client's cognitive impairment is a result of brain damage, and can attempt to identify the cause of the brain damage, such as Parkinson's disease, Alzheimer's disease, stroke, or long-term abuse of alcohol. Identifying the presence of a treatable dementia or determining the cause for brain damage helps clarify the older adult's prognosis and intervention options.

Although useful for clarifying potential causes of cognitive impairment and important for ruling out reversible causes of cognitive impairment, the effectiveness of psychological and neuropsychological exams in evaluating older adults' capacity to carry out certain activities (such as those necessary for continuing to live in their own homes) varies. Auditory and visual deficits can influence the older adult's ability to communicate and respond adequately to questions in a structured interview. Level of education can also positively or negatively affect scores. For example, mental status tests do not necessarily identify dementia in well-educated people who can score in normal ranges despite developing obvious deficits in other areas of function (Zarit & Zarit, 2007). Michael McCue (1997) discussed the relationship between neuropsychological testing and an individual's function. Although there is a relationship between an individual's scores on neurological tests and his or her ability to carry out activities of daily living, McCue stated these findings were not strong enough to support definitive predictions about any given individual's capacity to care for self, to perform specific instrumental tasks, or to predict how the individual might function in response to specific demands such as balancing a checkbook, paying rent, or operating a piece of equipment. This is because of, in part, the fact that neurological evaluations, psychiatric evaluations, and neuropsychological testing are often measures of disease and disability, not the individual's functioning (McCue, 1997).

In 2007, the ABA and APA developed an assessment template for clinicians carrying out capacity evaluations for adult guardianship hearings (Moye, Butz, et al., 2007). It includes areas of assessment that are broader than the traditional psychological and neuropsychological assessments and incorporates functional elements such as evaluating abilities to complete common activities of daily living. This is a positive development and a valuable contribution to the field of capacity assessment in working with vulnerable older adults.

The current text adds to the growing body of knowledge in the field of capacity assessment through its focus on capacity and functional assessment of older adults within the context of their social environment. This perspective is based on the "person-in-environment" (PIE) construct, the hallmark of social work assessment and intervention. The added dimension of "environmental context" requires social workers to also assess the "risks" inherent in the environment in which the older person lives. It is the combination of impaired capacity and environmental risks that informs social work assessment and intervention decisions.

Legal

"Capacity" refers to the assessment of ability in specific areas. A clinician who conducts an assessment of capacity for the court would comment on the person's abilities, whereas a judge would decide on competence. "Competence" and "incompetence“ are legal terms decided by a judge who has weighed all the evidence in a guardianship hearing. Guardianship is a legal proceeding undertaken to give a person or agency rights over another person who has diminished abilities to manage some or all of his or her personal or financial affairs (Mayhew, 2005). Although the particulars regarding how guardianship is dealt with differ from state to state according to state laws, the essential goal of the guardianship hearing is for the court to determine if the subject is incapacitated and whether a substitute decision maker needs to be appointed to act in an individual's best interest. When a person is determined to be incapacitated, the court considers if the guardianship would solve the issue (provide for the essential needs of the individual) and confirm there are no other feasible, less restrictive alternatives (ABA & APA, 2005; Mayhew, 2005). When these conditions are met, the court assigns a guardian as a substitute decision maker to act in the subject's best interests. Guardianship orders can be global or limited to the specific realms in which the person has been found to lack capacity (Zarit & Zarit, 2007).

Although the notion of what incapacitated means varies, most state laws have relied on some or all of the following three concepts: (1) the presence of a disabling condition; (2) level of functional behavior (ability to provide for personal needs); and (3) an evaluation of cognitive abilities or decisional capacity (Mayhew, 2005). The 1997 Uniform Guardianship and Protective Proceedings Act (UGPPA) offers the states a new framework for guardianship. The UGPPA provides a definition that removes the disabling condition and states that an "incapacitated person" is "an individual who is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance" (UGPPA, 1997). Although the framework and definitions provided have helped the movement toward national standards, each state can still decide independently if it wants to enact the UGPPA in its entirety, consider parts of it, or use none of it. The variation regarding individual state laws is further complicated by each state's interpretation of the language within the UGPPA that assesses incapacity in light of "appropriate technological assistance" as requiring a "necessity element" before a person will be judged incapacitated (Mayhew, 2005).

Zarit and Zarit (2007) summarized the legal statutes regarding competence as typically addressing four key points on capacity. First, capacity is presumed until a court decides otherwise. Second, capacity is evaluated for specific abilities. A person can be found to lack decision-making capacity for a single ability but could be considered capable of carrying out all other activities. Third, legal definitions of incapacity usually include four components: (1) presence of a disabling condition; (2) cognitive impairment; (3) functional impairment; and (4) the need for another party to intervene to prevent harm or other adverse consequences to the individual. And fourth, incapacity involves more than just eccentricity or engaging in risky behavior.

Over the last couple of decades, most states have modified protective laws to consider capacity rather than "competence" and implemented provisions for surrogate decision making of incapacitated adults by family members, powers of attorney, and other advance directive tools, without the need for court intervention. This has enabled family members and other appropriate surrogate decision makers to authorize needed care without having to go through a tedious and costly court process. This is effective in situations in which the impaired senior either agrees with the planned interventions, or in situations in which he or she is unable to communicate any disagreement. When a senior with impaired capacity disagrees with concerned family members or other involved professionals who are seeking to set up a surrogate decision maker, or when a senior with impaired capacity decides to terminate the authority of the surrogate decision makers already put in place, court proceedings to determine competency become necessary to override the senior's wishes and implement a care plan against his or her will.

There is a growing recognition of the conflicting complex issues involved in guardianship determinations for seniors who want to continue living in their homes but who are considered at risk and are resistant to accepting help. To reduce subjectivity, many states refined the threshold for incapacity determinations by changing from broad language considering one's "ability to take care of oneself" to more focused language regarding one's "ability to take care of the essential requirements for one's physical health or safety" (Sabatino, 1996, p. 11). The two standards that have developed and are now included in some state measures for evaluating capacity to remain at home are "essential needs," which is sometimes called "endangerment," and "least restrictive environment." "Essential needs" refers to whether a person is able to provide for his or her own basic requirements, such as food and housing, or whether his or her efforts to do so are so poor as to cause endangerment. The legal standard of living in the "least restrictive environment" recognizes that there are advantages to remaining at home that can offset risk, particularly if remaining at home is what the person wants and if he or she understands the risks involved. The implication of this standard is that risks associated with remaining at home need to be balanced against the benefits and risks associated with moving to a protected setting. The goal of least restrictive environment frequently conflicts with the preferences of some families, guardians, and judges to avoid any possible risk of harm to an older person (Zarit & Zarit, 2007).

EVALUATING CAPACITY AND "COMPETENCE": NOT JUST A LEGAL ISSUE

The presumption that evaluating when to intervene against someone's wishes (their capacity or "competence") is only a legal issue for the courts to decide is inaccurate. By tradition, the term "competence" referred to legal judgments and the term "capacity" referred to clinical determinations. This distinction, however, is not consistently reflected in either legal or medical usage (Appelbaum, 2007). Although situations requiring guardianship are resolved in a court of law, often the initial assessment on capacity and intervention decisions regarding whether or not to override the older adults' right to refuse help occurs before the legal system ever gets involved. In fact, it is probable that the majority of determinations of diminished capacity in older adults are made by clinicians, APS workers, social workers, and other professionals outside of the legal arena (Moye & Marson, 2007). For example, when social workers request temporary medical commitment of their clients, refer their clients to a legal agency requesting petition for appointment of a guardian, or coordinate their older clients' discharge from the hospital to a nursing home on the family's authority, the social workers have based these intervention decisions on their assessment of the older clients' capacity.

Many of the interventions social workers recommend for their vulnerable older clients are based on their own professional evaluation of their client's capacity. Because social workers are frequently on the front lines, they are often one of the professionals conducting assessments of vulnerable older adults living in the community, determining which cases to refer for emergency services and which cases to bring to the attention of attorneys and the court system for consideration of a surrogate decision maker. Each time the social worker implements a plan based on the wishes of the client, the social worker has made the decision that the client has the capacity to understand and is competent. In general, it is only when the social worker feels the client lacks the capacity that the process of formally evaluating capacity and considering protective interventions is considered.

Community social workers must often grapple with questions such as which community agency, if any, has the responsibility for responding to concerns about older clients who are at risk and refuse help. Social workers who work with vulnerable older adults should understand APS laws, the guardianship process, what is required of professionals in their state, and what limits or constraints are present on professional interventions with clients who resist accepting help. APS laws vary from state to state. Most state APS laws must balance the state's duty to protect its impaired citizens with civil rights of the individual citizen. Many situations fall outside the purview of APS laws. In addition to APS laws, some communities have separate guardianship laws, mental health laws, and other legal interventions. However, these laws rarely address the preliminary assessments and interventions that must occur before one determines that a particular legal intervention is appropriate, warranted, and in the best interest of the client.

Legal doctrine is based on a presumption of capacity, that adults are free to make their own decisions, including the decision to refuse medical and social services, unless they have been judged and determined incompetent by a court (ABA, APA, & National College of Probate Judges, 2006; Smyer, Schaie, & Kapp, 1996; Wolff, 1990). This creates a catch-22 situation for community social workers working with resistant older clients, as one may have to go through a long process of interventions prior to presenting a case for surrogate decision making, or, if necessary, a legal competency hearing. Strict adherence to legal guidelines (and social work values of self-determination) might suggest that no intervention with clients who are refusing the assistance, including assessment, can legitimately be undertaken prior to a court's involvement. A well-respected legal authority on capacity assessment in the elderly raised the issue of examining "the policy of whether professionals ought to be encouraging or discouraging extralegal 'bumbling through' handling of persons with questionable capacity rather than routinely initiating formal judicial involvement through the guardianship process" (Kapp, 2003, p. 83). This perspective highlights the need for social workers to more clearly articulate their role and professional competencies in working with vulnerable older adults. The social worker's determination of when it is appropriate to "initiate formal judicial involvement" is anything but "routine" or a process of "bumbling through."

The social worker's comprehensive assessment of vulnerable older adults' capacity and function is vital in clinical, family, community practice, and the judicial process. Social workers provide information on family structures, family functioning, and the quality of family relationships that is critical when considering issues related to surrogate decision making. In geriatric community-based practices, many potential guardianship cases do not result in guardianship petitions because social workers work with attorneys and other professionals to implement interventions that provide "less restrictive alternatives" to court interventions. These alternative interventions attempt to strike a balance between their clients' coping ability and their environmental demands, and usually seek to ensure clients' safety and protection, while maximizing clients' autonomy, independence, and involvement in decision making.

SUMMARY

The changing demographics of our aging society will result in a need for education and training of more social workers to work effectively with the older population. Vulnerable older adults who are at risk and resistant to accepting help present especially challenging dilemmas for community professionals. Resolving the issues raised by these situations requires careful consideration of individual and professional value systems and mastery of professional skills for working with this population.

We have traditionally looked to the fields of law, medicine, psychology, and neuropsychology to guide us on assessment of cognition and decisional capacity. Although relevant, they do not fully address the issues present when evaluating capacity in older adults within the context of their environment. There is a need for more tools and models based on social work concepts to guide practice with vulnerable older adults.